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Nurse Led End of Treatment Clinic for Patients Completing the Main Phase of Their Treatment for Early Breast Cancer Guideline

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Brief Summary of document:	This document provides guideline for implementing and running a nurse led end of treatment clinic for patients completing the main phase of their treatment for early breast cancer
Scope	This guideline should be used by the Breast Care Nursing Team as a guide for developing, implementing and running the nurse led end of treatment clinic for patients completing the main phase of their treatment for early breast cancer. The procedure can be used as a guide for this service, providing operational details for interested parties.
To be read in conjunction with:	
Owning Committee/ Group	Breast Multi-Disciplinary Team

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REVIEWS & UPDATES

Version no:	Summary of Amendments:	Date Approved:
1	New Procedure	21/12/2016

GLOSSARY OF TERMS

Term	Definition
HOPE	Helping to overcome problems effectively

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1. INTRODUCTION

The end of treatment clinic will provide a formal structured approach to ensure that all patients completing treatment have a holistic needs assessment and written care plan. The aim of the appointment is to identify unmet needs and patient priorities, to encourage self care and empowerment, and facilitate a positive recovery following treatment for breast cancer, planning strategies to achieve patient priorities in line with the wider national rehabilitation and survivorship agenda.

This clinic will be a nurse led clinic and will be run by a Breast Care Clinical Nurse Specialist. It will form part of the formal follow-up pathway for patients diagnosed with early breast cancer (Appendix 1).

2. AIM

The aim of this guideline is to provide guidance for the Breast Care Nursing Team to develop, implement and run a nurse led end of treatment clinic for patients completing the main phase of their treatment for early breast cancer.

The aim of the end of treatment clinic is for the Clinical Nurse Specialist to undertake an individual holistic needs assessment for all patients completing the main phase of their treatment for early breast cancer.

3. OBJECTIVES

This guideline will provide specific guidance for the Breast Care Clinical Nurse Specialists relating to eligibility criteria, referral processes, holistic assessment of patient needs and the planning of care.

4. SCOPE

The guideline is applicable across Hywel Dda, currently the service is provided by the Withybush Breast Care Nursing Service. The service is accessible to patients who have been diagnosed with early breast cancer. This is a nurse led service that provides a follow-up pathway for patients who have been diagnosed and treated for early breast cancer. The service is provided by an experienced Clinical Nurse Specialist.

For the purpose of this clinic, the end of treatment is being defined as patients who have completed the main phase of their treatment for early breast cancer, for example surgery, chemotherapy and radiotherapy. Patients may still be having trastuzumab (herceptin) or continuing on endocrine therapy. There may be other patients who are continuing anti-cancer therapy within the context of a clinical trial; these patients are eligible for this service.

Inclusions criteria:

- All patients with early breast cancer i.e. stage I, II and III disease who have completed the main phase of their treatment for breast cancer.

Exclusions criteria:

- Patients with metastatic disease i.e. stage IV disease.

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5. REFERRAL TO THE END OF TREATMENT CLINIC

As it is recognised that all patients have individual treatment plans, the procedure for referral to the 'End of Treatment Clinic' will be via the multidisciplinary team meetings and results clinics as identified by the nursing teams.

Once identified, the patient will be sent an invitation letter, detailing an appointment date and time (Appendix 2).

6. CLINIC TEMPLATE, STAFFING AND STRUCTURE

The clinic is staffed by an experienced Breast Care Clinical Nurse Specialist. The patients will be booked into hourly appointment slots.

7. CLINIC PROCEDURE

7.1 CLINIC CONSULTATION:

The clinic consultation will allow patients to discuss:

- Their overall treatment.
- Their plan for follow-up care and mammography.
- Any ongoing treatment – for example hormone therapy.
- Any ongoing physical and psychological concerns relating to their breast cancer diagnosis and treatment.
- Programmes and services that are available to them to support their recovery.
- Any other information they need at this time.
- Who they should contact and how in the event that they have any concerns.
- Discussion of breast awareness following breast cancer treatment and reporting signs and symptoms of a recurrence.
- Reiteration of who patients should contact and how, if they have any concerns.

Following the consultation, the patient will receive a plan for their ongoing care which summarises the discussions that have taken place.

7.2 HOLISTIC NEEDS ASSESSMENT

All patients will be provided with a paper copy of the Macmillan Holistic Needs Assessment Form (HNA) (Appendix 3) on arrival for their appointment, and asked to complete it prior to the appointment.

8. CARE PLAN

All patients will be offered a copy of their treatment and follow-up summary. Their care plan will be sent to them following the consultation. With the patient's permission a copy of their care plan will be sent to the GP (Appendix 4 and 5).

Macmillan's Care Plan template will be used to complete the written care plan following each appointment (Appendix 5).

9. SELF MANAGEMENT PROGRAMMES AND FURTHER SUPPORT

A key part of this service is identifying unmet need in patients and highlighting self management services to patients to address issues. All patients will be given verbal and/or written information about the following services:

- Breast Cancer Care 'Moving Forward' Programme.
- Macmillan Helping to Overcome Problems Effectively (HOPE Course).
- Adam's Bucket Full of Hope Services.

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- Pembrokeshire Cancer Support Services.
- Look Good Feel Better Workshops.
- National Exercise Referral Scheme.
- Other services relevant to needs (Appendix 6).

Through holistic assessment of patients, the need for onward referral to psychological oncology support services and allied health professionals may also be identified. The Clinical Nurse Specialist is responsible for carrying out the assessment to initiate these referrals.

10. STORAGE OF DOCUMENTATION AND SHARING OF INFORMATION

Copies of the care plan records will be stored in the patients medical notes. All patients will be asked whether their GP can receive a copy of the care plan for their records. A copy will also be stored in the Breast Care Nursing notes.

11. TRAINING

The Clinical Nurse Specialist for Breast Care is professionally accountable for providing this service. The competency requirements are contained with the role profile and monitored during the annual appraisal process and via the NMC revalidation process.

12. IMPLEMENTATION

The clinic is currently operational and the service is being evaluated using a patient satisfaction questionnaire. (Appendix 7).

13. FURTHER INFORMATION

- South Wales Cancer Network (2013) The Management of Breast Cancer. Singleton Hospital Swansea, South Wales Cancer Network
- Reference list or contact the Macmillan Breast Care Clinical Nurse Specialist.

14. REFERENCES

Hywel Dda Health Board (2012) Hywel Dda Health Board's Cancer Delivery Plan 2013 – 2016. Accessed via Hywel Dda University Health Board Web Site.

National Institute for Health and Care Excellence (NICE) (2009) Early and Locally Advanced Breast Cancer: Diagnosis and Treatment. NICE Guidance CG80. London, NICE.

South Wales Cancer Network (2015) The Management of Breast Cancer. Singleton Hospital Swansea, South Wales Cancer Network.

Snowden, A. and White, C. (22.10.14) Assessment and Care Planning for Cancer Survivors. A Concise Evidence Review. London, Macmillan Cancer Support.

Wales Cancer Intelligence and Surveillance Unit, Macmillan Cancer Support and National Cancer Intelligence Unit (2015) Collaboration Reveals the True Scale of People Living With Cancer in Wales. Reported on 8th June 2015 on Hywel Dda University Health Board Web Site.

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15. APPENDIX 1 - WITHYBUSH GENERAL HOSPITAL FOLLOW-UP PATHWAY FOR EARLY BREAST CANCER PATIENTS.

(June 2015)

3 – 6 months After End of Treatment	Year 1 or Follow-Up	Year 2,3,4 of Follow-Up	Year 5 of Follow-Up
Review By Breast Care Clinical Nurse Specialists	Patients Seen By Member of the Surgical Team and Mammogram	Annual Mammogram, Patients Do Not Require An Appointment	Patients Seen By Member of the Surgical Team, Mammogram and Endocrine Therapy review.

- Patients will have open access to contact the Breast Care Clinical Nurse Specialists if they have worries/concerns and will be advised accordingly.
- Patients aged 50 will automatically re-access Breast Test Wales Screening Programme following discharge from the Primary diagnosis follow-up programme.
- Following treatment for early breast cancer, patients who are diagnosed under the age of 50 will continue to have annual mammography until they reach screening age.

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16. APPENDIX 2 - INVITATION LETTER TO THE END OF TREATMENT CLINIC

Ein cyf/Our ref:
Gofynnwch am/Please
ask for:
Rhif Ffôn /Telephone:
Ffacs/Facsimile:
E-bost/E-mail:
Dyddiad/Date:

Dear

As you are at the end of the main phase of your breast cancer treatment, you are invited to attend an end of treatment clinic on Tuesday -----at ----- . The clinic is held in the_____. Please report to main Outpatients and you will be directed from there.

The purpose of this clinic is to help you plan any ongoing care and support you and your family may need once your treatment has finished. During the consultation, you will have the opportunity to discuss:

- your overall treatment
- any on going treatment – for example hormone therapy
- any on going physical and psychological concerns relating to your breast cancer diagnosis and treatment
- programmes and services that are available to you to support your recovery
- your plan for follow-up care and mammography
- any other information you need at this time
- who you should contact, and how, if you have any concerns.

Your appointment will be with_____, and it forms part of your follow-up plan. The consultation will take about 45 minutes. Please feel free to bring somebody with you if you wish to.

Following the consultation, you will receive a plan for your ongoing care which summarises the discussions that have taken place. If you have any questions, or you are still receiving treatment such as chemotherapy or radiotherapy treatments when the appointment is scheduled, or if you are unable to make this appointment, please ring the

Yours sincerely

17. APPENDIX 3 - HOLISTIC NEEDS ASSESSMENT

National Cancer Survivorship Initiative – Concerns checklist

Holistic needs assessment

Identifying your concerns

Discussed by: _____

Date: _____

Designation: _____

Contact details: _____

Patient's name or label

This self assessment is optional, however it will help us understand the concerns and feelings you have. It will also help us identify any information and support you may need in the future.

If any of the problems below have caused you concern in the past week and if you wish to discuss them with a health care professional, please tick the box. Leave the box blank if it doesn't apply to you or you don't want to discuss it now.

I have questions about my diagnosis/treatment that I would like to discuss.

Physical concerns

- Breathing difficulties
- Passing urine
- Constipation
- Diarrhoea
- Eating or appetite
- Indigestion
- Sore or dry mouth
- Nausea or vomiting
- Sleep problems/nightmares
- Tired/exhausted or fatigued
- Swollen tummy or limb
- High temperature or fever
- Getting around (walking)
- Tingling in hands/feet
- Pain
- Hot flushes/sweating
- Dry, itchy or sore skin
- Wound care after surgery
- Memory or concentration
- Taste/sight/hearing
- Speech problems
- My appearance
- Sexuality

Practical concerns

- Caring responsibilities
- Work and education
- Money or housing
- Insurance and travel
- Transport or parking
- Contact/communication with NHS staff
- Housework or shopping
- Washing and dressing
- Preparing meals/drinks

Family/relationship concerns

- Partner
- Children
- Other relatives/friends

Emotional concerns

- Difficulty making plans
- Loss of interest/activities
- Unable to express feelings
- Anger or frustration
- Guilt
- Hopelessness
- Loneliness or isolation
- Sadness or depression
- Worry, fear or anxiety

Spiritual or religious concerns

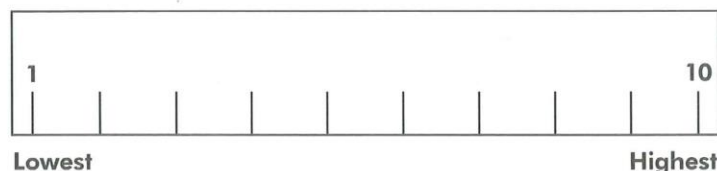
- Loss of faith or other spiritual concern
- Loss of meaning or purpose of life
- Not being at peace with or feeling regret about the past

Lifestyle or information needs

- Support groups
- Complementary therapies
- Diet and nutrition
- Exercise and activity
- Smoking
- Alcohol or drugs
- Sun protection
- Hobbies
- Other

Please mark the scale to show the overall level of concern you've felt over the past week.

You may also wish to score the concerns you have ticked from 1 to 10.



**WE ARE
MACMILLAN.
CANCER SUPPORT**

(DH) Department
of Health

NHS

NHS Improvement

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18. APPENDIX 4 - TREATMENT AND FOLLOW-UP SUMMARY



Your Personal Summary Plan of your Treatment and Follow-Up

This summary is for you to update and hold as an information overview for your own care.

You can take this to your appointments.

You can show this booklet to any healthcare professional(s) you wish to.

NB : it is not intended for use as a complete or comprehensive record of your care

NAME:	Patient Number(s):	
My diagnosis:	Tumour Type:	Grade/Size:
	Number of lymph nodes affected by cancer:	

MY CONTACTS	
Breast Care Nurse Team / Key Workers	
My Surgical Team	
Oncology Nurse Practitioners	
Chemotherapy Day Unit, Withybush General Hospital	

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TREATMENT CARE PLAN

Treatment plan

SURGERY		CHEMOTHERAPY		RADIOTHERAPY		TRASTUZUMAB (HERCEPTIN®)		ENDOCRINE / HORMONE	
YES	NO	YES	NO	YES	NO	YES	NO	YES	NO

Information about my treatment

SURGICAL PROCEDURE(S)		
Date	Procedure	Side

CHEMOTHERAPY TREATMENT			
Treatment :			
_____cycles are intended and I will receive _____ cycle every _____ weeks			
Start date		Finish date	

RADIOTHERAPY TREATMENT			
Treatment :			
_____fractions are intended and this will be for _____ days			
Start date		Finish date	

TRASTUZUMAB (HERCEPTIN®) TREATMENT			
Start Date		Finish Date	
Trastuzumab (herceptin®) treatment is usually given every 3 weeks			

ENDOCRINE / HORMONE TREATMENT	
Medication (name)	
Planned duration of treatment	

REFERRALS	DATE

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AFTER TREATMENT PLAN

What can I do when I finish treatment?

Attend after treatment course

<p>'HOPE' is a six week self management programme, to help you set positive goals for the future and get more out of life. It cover ALL cancers</p>	 	<p>To BOOK</p> <p>Tel: 01656 867960</p> <p>Email: WalesLearning@macmillan.org.uk</p>
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<p>'Moving Forward' is a 4 week course specifically for breast cancer patients, helping to approach life after treatment with confidence.</p>		<p>To BOOK</p> <p>Tel: 0345 077 1894</p> <p>Email: cym@breastcancercare.org.uk</p>
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MY FOLLOW-UP PLAN CONSISTS OF

You will be followed up for _____ years from the date of your diagnosis

FOLLOW-UP PLAN	HOW OFTEN

MAMMOGRAM REQUIRED	HOW OFTEN
	years

<p>ENDOCRINE / HORMONE THERAPY TREATMENT</p> <p>NB – This is part of your treatment and you should continue unless directed otherwise by a clinician</p>	<p>DURATION</p> <p>months / years</p>	
Drug name	Start date	
Drug name	Start date	
<p>BONE HEALTH (DEXA) CHECK REQUIRED</p> <p>This is REQUIRED for some patients on certain ENDOCRINE THERAPY TREATMENTS</p>	YES	NO

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If you or your GP have any CONCERNS during your follow-up please contact the Breast Care Nurse Specialists on _____ SUPPORTIVE CARE

WELFARE SUPPORT	
This service can assist you with any general enquiries or information you may have. This service can give general information of aspects of sickness reporting and entitlements, benefits or grants enquiries. It can also help you with information on returning to work and travel insurance.	
Contact	Macmillan Welfare Benefits Advisor Tenovus Welfare Benefits Advisor 0808 8081010 or your Breast Care Clinical Nurse Specialist

COMPLEMENTARY THERAPIES	
You may wish, during your treatment to request a referral to healthcare professionals within the breast treatment service that can help with queries you may have on exercise, how you are feeling emotionally, Lymphoedema, managing fatigue, nutrition, or your general health.	
Contact	Breast Care Clinical Nurse Specialist

EXERCISE	
You may wish, after your treatment to request a referral to the Wales National Exercise Referral Scheme (NERS) Cancer Pathway in order to increase your fitness .	
Contact	Breast Care Clinical Nurse Specialist

HOLISTIC NEEDS ASSESSMENT (HNA) – PERSONAL CARE PLAN	
A focus on you and how you are feeling	
A HNA is an opportunity for a discussion with your breast nurse / key worker to talk about any concerns. These may include (but are not limited to); Relationships Symptoms Physical concerns Feelings Emotions Money worries	A HNA may be offered at various times during your care, including: Diagnosis Pre-Surgery Start / end of your treatment(s) Or any time you ask for one

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Adam's Bucket Full of Hope	
Breast Cancer Care	
Lymphoedema Prevention Team	
Macmillan	
Macmillan Cancer Information and Support Service – Withybush Hospital	
Maggie's Swansea	
Marie Curie	
Oncology Nurse Practitioners	
Paul Sartori	
Pembrokeshire Cancer Support	
Tenovus	
Transport Booking Centre	
MY CONTACTS	
My GP Practice	

**CONTINUE TO BE BREAST AWARE
SIGNS AND SYMPTOMS TO LOOK OUT FOR AND SEEK ADVICE ON:**

In relation to the breast and chest area:

- Change in shape or size.
- Lumpy area or thickening on scar line that feels different.
- Lumpy area in axilla/arm pit or around your collarbone.
- Redness or rash on the skin and/or around the nipple.
- Weepy ulcer on treated breast.
- Dry crusty area/itchy.
- Nipple discharge.

Other symptoms to seek advice about:

- Pain that does not improve with pain relief.
- Dry cough which persists.
- Feeling breathless.
- Feeling constantly tired.
- Constant feeling of nausea/sickness.
- Sudden weight loss without trying to.
- Loss of appetite.
- Severe headaches.
- Altered vision or dizziness.

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19. APPENDIX 5 - CARE PLAN TEMPLATE

National Cancer Survivorship Initiative – Concerns checklist

Care plan

Completed by: _____
 Date: _____
 Designation: _____
 Contact details: _____

Patient's name or label

Level 1: Score 0–3 Mild concerns

Discuss sources of concern with the patient, include information, contact details and monitor.

Level 2: Score 4–6 Moderate concerns

As above for level 1 and provide information and discuss with a colleague if necessary and signpost to support. Use second level assessment tool if appropriate eg HADs.

Level 3: Score 7–10 Significant concerns

As above in Level 1 and 2 and use second level assessment tool if appropriate eg HADs and refer to specialist services if required.

Overall score on the scale: _____

Main concerns	Score	Description of concern	Plan of action

Copies sent to:

Next review due:



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20. APPENDIX 6 - SERVICES AVAILABLE TO SUPPORT PATIENTS NEEDS

Identification of Services Available to Patients on Completion of Early Stage Breast Cancer

Problem Identified	Resources Available For Support
Psychological Distress	Acute Psychiatric Services Accessed via the Accident and Emergency Department or via GP Assessment. Advised Individuals to Seek Ongoing Assessment and Management Via GP. Breast Services Psychologist Referral to the Tenovus Counselling Services.
Lymphoedema Management	Re-referral to the Lymphoedema Prevention Team.
Limited Arm/Shoulder Mobility/Stiffness Following Treatment	Referral to local Physiotherapy Services. Referral to the Lymphoedema Prevention Team
Increasing Physical Activity and Fitness	Referral to the Welsh National Exercise Referral Scheme.
Financial and Welfare Advice	Referral to the Macmillan or Tenovus Welfare and Benefits Advisor.
Fatigue Management	Oncology and Palliative Care Occupational Therapist offers Individual Support to Discuss Fatigue Management.
Rehabilitation Programmes	Referral to the 'Moving Forward' Programme run in association with Breast Cancer Care and Withybush Breast Care Nursing Services. Referral to the 'HOPE' Programme run by Macmillan locally. Young Women's Support Programme. Self-referral to the Breast Cancer Care Peer Support Programme.
Body Image Concerns	Referral to the 'Look Good Feel Better' Masterclass run in association with the Withybush Breast Care Nursing Service. Referral to the Body Image and Sexuality Counsellor. Prosthesis fitting via Withybush Breast Care Nursing Services. Referral for Breast Reconstructive Services via Morriston Hospital.
Isolation and Increasing Peer Support	Information on Local Third Sector Organisations Including Pembrokeshire Cancer Support and Adam's Bucketful of Hope. Breast Cancer Care Peer Support Macmillan Cancer Support

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Menopausal Symptoms	Breast Care Clinical Nurse Specialist to Review Needs 'Moving Forward' Course
Sexual Concerns	Breast Care Clinical Nurse Specialist Referral to the Body Image and Sexuality Counsellor.
Diet and Weight Loss	Diet and Breast Cancer Information Booklet. Referral to the Community Dietetics Service.
Alcohol Advice	Dyfed Drug and Alcohol Services
Smoking Cessation	Hywel Dda University Health Board Smoking Cessation Services Stop Smoking Wales/Dim Smygu Cymru
Children's Adaption to Diagnosis	Counselling Services Available Within All Secondary Schools – Self Referral/ Health Care Professional/Parent Referral. Sandy Bears Childrens Loss and Bereavement Services.
Contraception Advice	Hywel Dda Health Board Sexual Health Services
Additional Information Resources	Macmillan Cancer Information and Support Services.

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3. What, if anything, would you change about the clinic?

4. Is there anything else that you would like to tell us about the clinic which would help us improve it for future patients?

Thank you for your time and we wish you the very best for the future.

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